

The Road Ahead: Next Exit Hope!

A look at how brain injury affects the whole family



For ages 5 to 10



Fraser Valley Brain
Injury Association



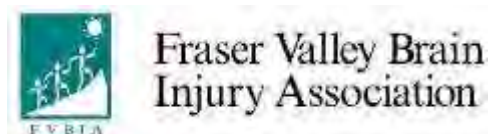
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Developed for the Fraser Valley Brain Injury Association by: Jodie Millward and Carol Paetkau

Edited: Carol Paetkau
Cover Design by: Carol Paetkau



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Names have been changed or omitted to protect the privacy of the artists and their families.

For information on using this resource, please contact
Fraser Valley Brain Injury Association
201 – 2890 Garden Street Abbotsford, BC, V2T 4W7

Phone: 604-557-1913 Fax: 604-850-2527 Email: info@fvbia.org Website: www.fvbia.org



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Introduction

When someone we love gets hurt the first question is “are they going to survive”? When everything is done to save their life and the doctor says “they are going to live”, a sense of relief overwhelms the family. This is the beginning of a new chapter in a family’s life.

From the beginning it’s clear that an injury affects the whole family, especially when it’s as serious as an acquired brain injury. There are so many questions and not enough answers.

This booklet will not provide all the answers but will serve as a guide for families who are new to acquired brain injury.

This material is geared towards children ages 5 to 10 years old that have a sibling or a parent with an acquired brain injury. It is designed to be interactive in order to help children relate the information to their own thoughts and feelings. It can be helpful for parents go through with their child to use as a tool to talk about brain injury and any feelings the child might be experiencing.

The “Parents Only!” section is designed to give parents some ideas about how to help their children understand what is happening in their family.



The “In the Words of Survivors” section contains comments from children and adults who have had acquired brain injuries.

These quotes may help you understand what their struggles, experiences and hopes for the future are.

This booklet is filled with stories, art, thoughts and feelings shared by real people of all ages who have experienced acquired brain injury in their family.

What is an Acquired Brain Injury?

An acquired brain injury is when your brain gets hurt. There are lots of ways that you can hurt your brain:

- Ⓞ Hitting your head when you fall off your bike, skateboard, or scooter.
- Ⓞ Car crashes.
- Ⓞ Brain tumour
- Ⓞ **And lots of other things...**

Note: Now you know why it is really important to stay safe by wearing a helmet when you are skateboarding, biking, playing hockey, football, etc.



Why is your Brain so Important?

The brain is the boss of your body! It controls everything including:

- Ⓞ Your legs
- Ⓞ Your arms
- Ⓞ What you see
- Ⓞ What you think

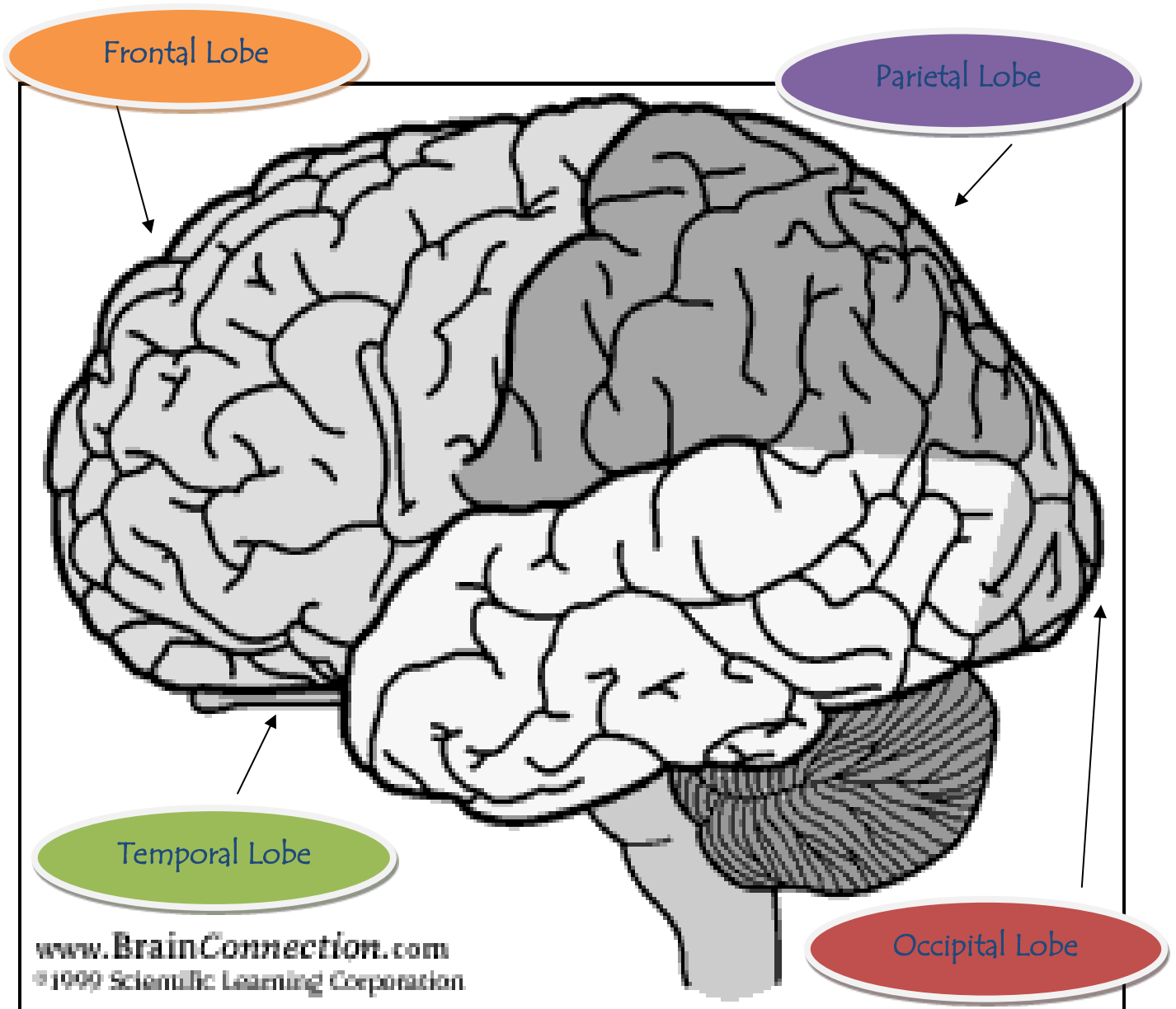
Since your brain is very important for everything you do, people with a brain injury can be different than they were before. They might:

- Ⓞ Have parts of the body that don't work the same
- Ⓞ Have trouble remembering things (like names, friends or even family)
- Ⓞ Be grumpy or angry a lot
- Ⓞ Say or do things they don't mean to
- Ⓞ May not seem like the same person
- Ⓞ Sleep more

What Happens when your Brain gets Hurt?

Can you Colour the Different Parts of the Brain?

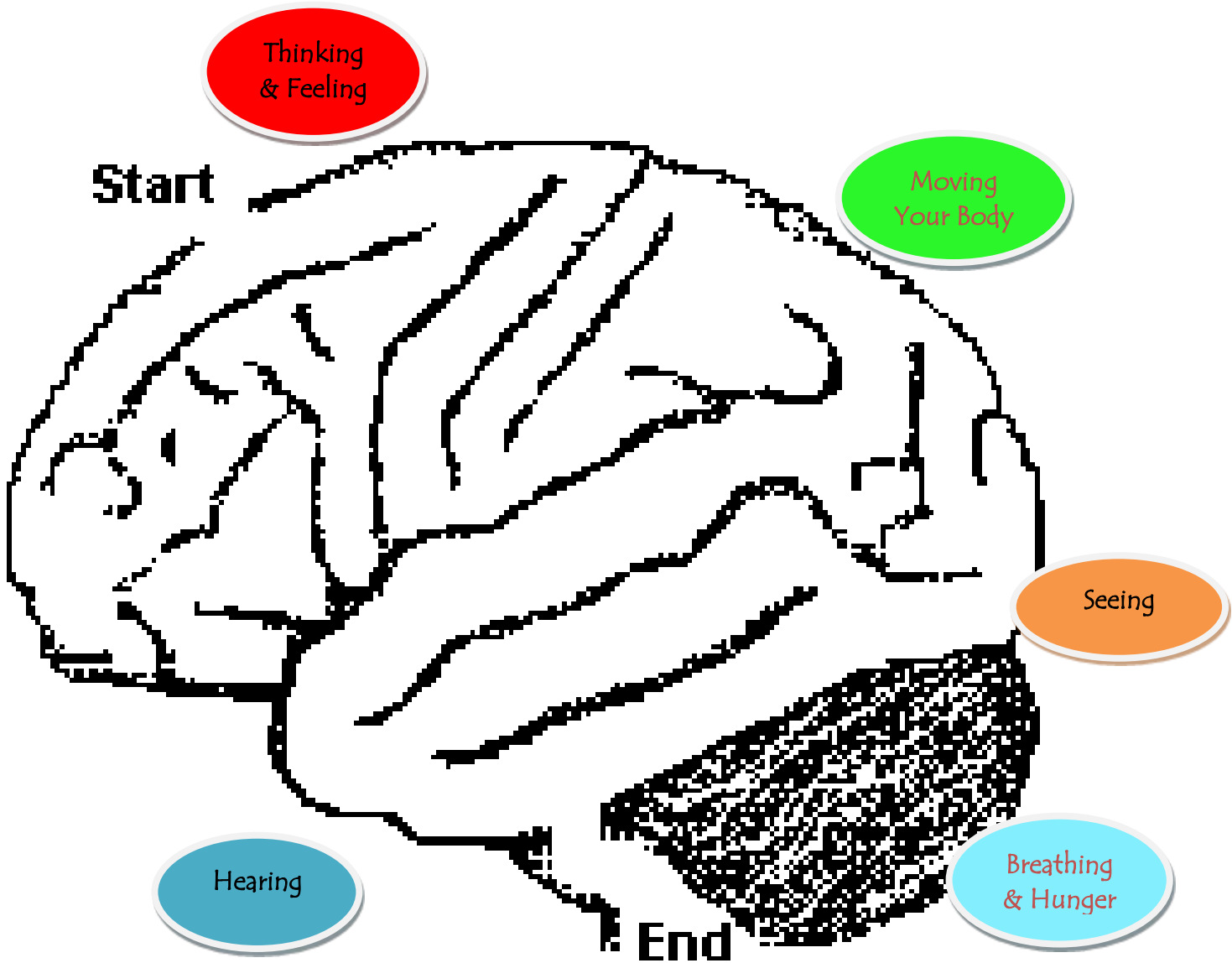
This is a picture of the brain. The different shaded areas are the different parts (lobes) of the brain. Each lobe has its own job.



The Brain Maze

In order for your body and mind to work properly, all the parts of your brain have to work together. These are just some of the things your brain can do.

See if you can find your way from Start to End.
Find out which parts of the brain do what!



When Your Mom or Dad gets Hurt.

Our Moms and Dads can be the most important people in our lives. They take care of us, love us and we need them more than anything. Sometimes, because of brain injury from an accident or sickness, our moms or dads change. This can be very scary.



Things Seem Different Now

After your mom or dad has a brain injury, they might act differently or seem a little strange. Things might seem different at home because of all the changes.

Some new things might be:



- Ⓢ You have to be a lot more quiet
- Ⓢ Your mom or dad don't play like they used to
- Ⓢ There is some medical equipment in the house
- Ⓢ They might not be able to drive
- Ⓢ They might lose their friends
- Ⓢ They might be sad or angry more
- Ⓢ You might need to help around the house

It can feel like your home has changed so much that it doesn't really feel like your home anymore and that can make you sad, angry or scared. Those kinds of feelings are normal.

Can you think of some things that have changed around your home?
Can you write them down in this box?

In the Words of Children

Drawing pictures or writing stories about your feelings can help you feel better. The art and feelings throughout this book are from kids that have experienced brain injuries in their families and they wanted to share them with you.

"Now I always feel like I live in a volcano, I never know what is going to happen next and things are so much different than they were before."



When your Brother or Sister gets Hurt

Having brothers and sisters isn't always easy but when one gets hurt, things sure can change around your home.

Some of the things that might have changed since your brother or sister got hurt might be:

- Ⓞ They act differently
- Ⓞ They need a lot of extra help from everybody
- Ⓞ They are angry or sad a lot
- Ⓞ They sleep a lot
- Ⓞ They can't walk, talk or eat by themselves
- Ⓞ They don't have any friends
- Ⓞ There are strangers around the house

Things that have changed

What are some changes at your house since your brother or sister was injured?
Can you write them down in this box?

Things that Have Changed:

Handwriting practice box with a green background and a dashed black border. It contains several horizontal lines for writing.



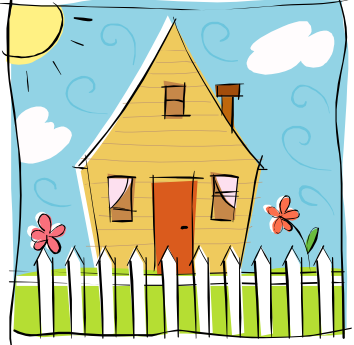
You might feel like you are not as important as you were before your brother or sister got hurt.

This is not true!

You are just as important as your brother or sister. They just need more help because of the injury.

In the Words of Brothers and Sisters

"My sister is annoying and gross!
I spend a lot of time trying to get away from her as much as I can!"



"This is the home and family I hope my brother can have one day..."

Important Things to Remember About Brain Injuries!

- Ⓞ No two brain injuries are ever the same.
- Ⓞ When one person in the family gets hurt, things will change things for every person in the family.
- Ⓞ The most healing happens in the first couple of years, but healing doesn't stop. It just may seem like it is slowing down.
- Ⓞ A brain injury isn't obvious like a broken arm or leg so people might think the person should just "get over it".
- Ⓞ The brain can learn new ways to do old things.
- Ⓞ Celebrate even the tiniest improvements.



Why are there so many people around?

Many different professionals will be coming in and out of your life but remember that they are all there to help you and your family. These might be:



- Ⓞ Physical Therapists
- Ⓞ Occupational Therapists
- Ⓞ Kinesiologist
- Ⓞ Doctors
- Ⓞ Nurses
- Ⓞ Psychologists
- Ⓞ Psychiatrists

What am I Feeling?

It's sometimes really hard to talk about our feelings because we might not know what they are or what they mean. It's normal for your body and thoughts to tell you that something isn't quite right when you are upset, but you may not understand what that feeling is.

These emojis show some of the feelings you might be having.



happy



angry

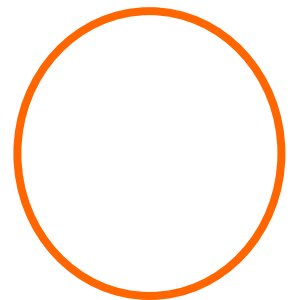
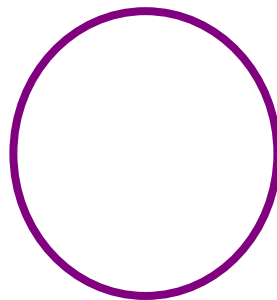
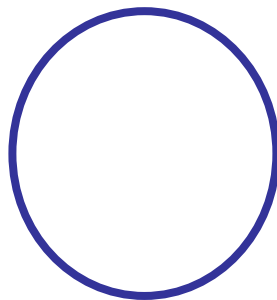
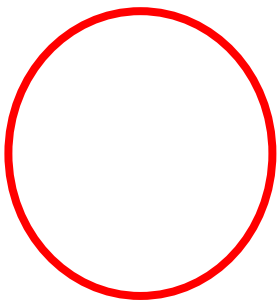


sad



frightened

Can you draw some of your feelings by making faces in the circles below?



Remember, your feelings can change from one minute to the next or from day to day!

Feelings are Complicated!



"I have layers of feelings... some good and some bad.
Sometimes I'm angry and I don't know why..."

I Feel Confused!

Everybody is working very hard to help you and your family through this hard time. It's okay to ask questions and give out as many hugs as you think everybody needs and to get some yourself!

It may seem like some of your family is sad and others are mad and that you are not sure what is happening.



What kinds of things can you do to help you feel better? Sometimes they are just the things that we like to do all the time.

- @ Write stories or letters
- @ Talk about your feelings
- @ Cuddle with a favorite pet
- @ Listen to music
- @ Play with a friend or favorite toy
- @ Play a sport
- @ Get a hug
- @ Play a video game

What can I do to Feel Better?



Things I Like to do:

A large green rectangular area with a dashed black border, containing several horizontal lines for writing a list of activities.

Can you think of some other things you do that that make you feel happy?

Let's make a list!

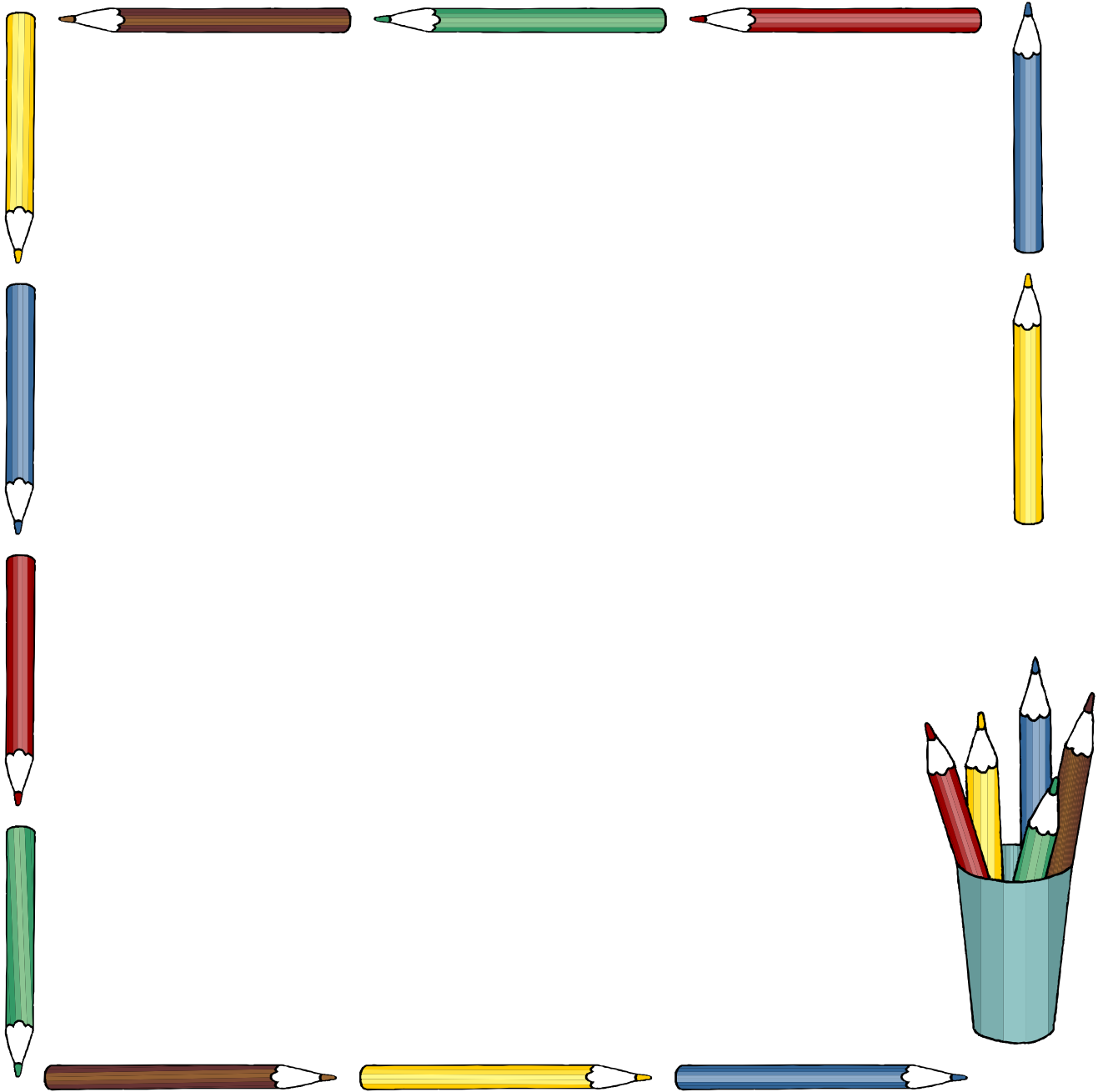
Share your list with your family and see if they can make one too!

When you are feeling upset, try taking out your list and do something on it.

What do I do with these feelings?

Do you like to paint or draw? It can help to draw or paint pictures when you are upset or having a hard time talking about your feelings.

In the box below, try to draw a picture of something you are feeling right now.



Who can I Talk to About my Feelings?

- 👤 Parents
- 👤 Grandma or Grandpa
- 👤 Friends
- 👤 Older brother or sister
- 👤 Teachers
- 👤 Doctors
- 👤 Nurses
- 👤 Counsellor
- 👤 Grownups that you feel safe with
- 👤 Talk to someone at the Kidshelphone line. <https://kidshelpphone.ca/>
[1800 668-6868](tel:18006686868) [Text 686868](sms:686868)



Sometimes it's hard to know when it would be a good time to talk about your feelings. Here are a few tips to help you decide:

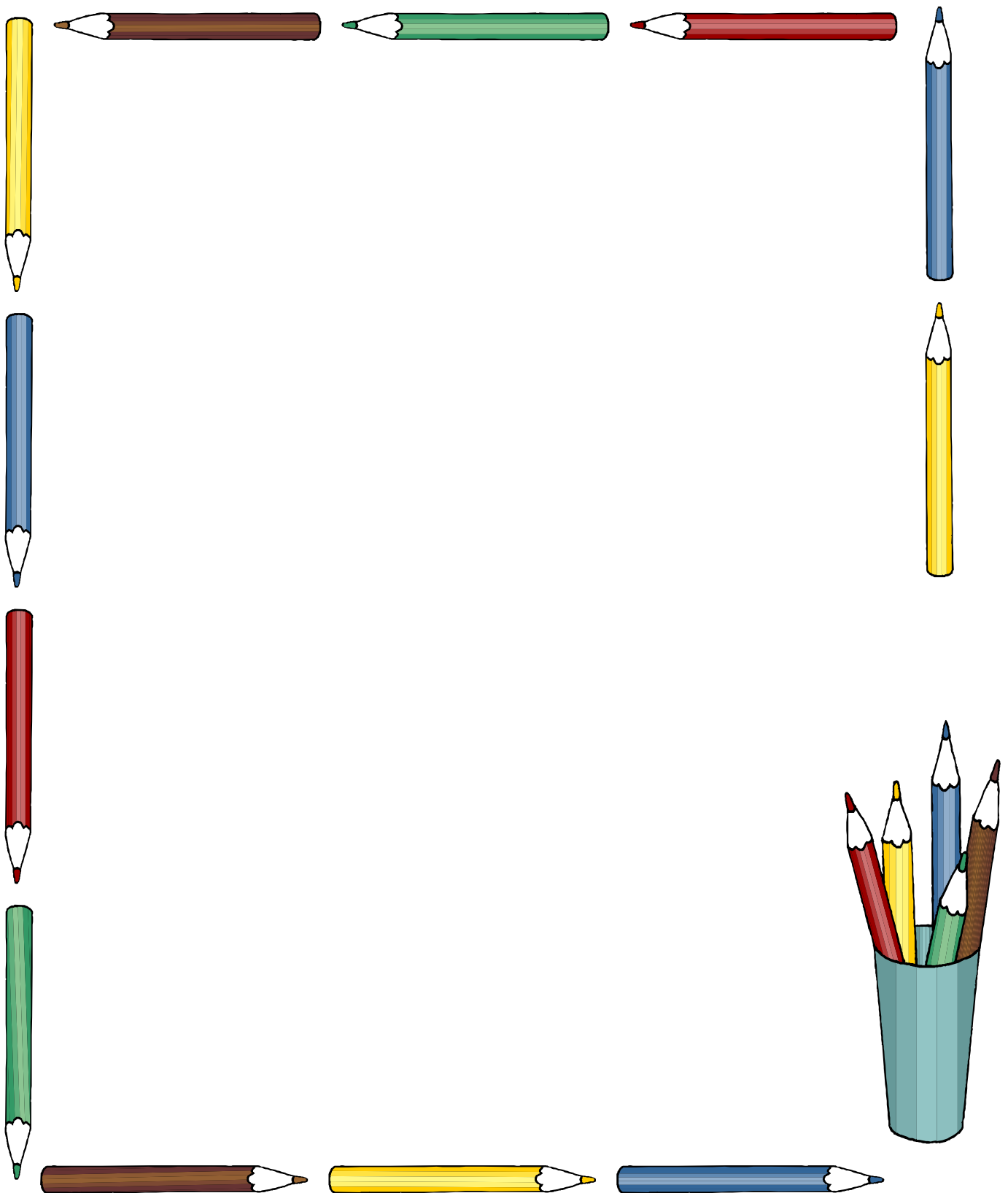
- 👤 Pick a time when it is quiet and calm.
- 👤 Ask when a good time would be to talk.
- 👤 Start with "I feel..." (sad, mad, upset, happy, confused, scared...)
- 👤 Use pictures or stories that show how you feel and talk about them.

How can I Share my Feelings?

REMEMBER

There are no right or wrong feelings.
Share your feelings with somebody you trust.

Can you draw a picture of someone you feel safe talking to about your feelings?



Happy Places

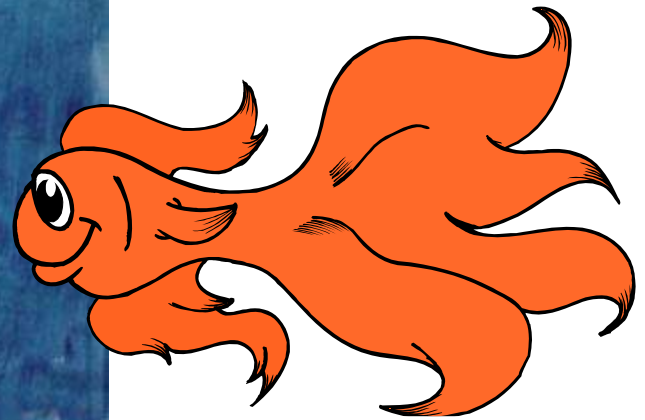
Sometimes you might even feel like you would rather live anywhere else but here. It's okay to imagine other places that we can go to in our imagination. These are our happy places.



"I would live in the middle of nowhere
all by myself. Nobody would yell at me
or get angry with me. I wouldn't feel like
I am in the way all the time.

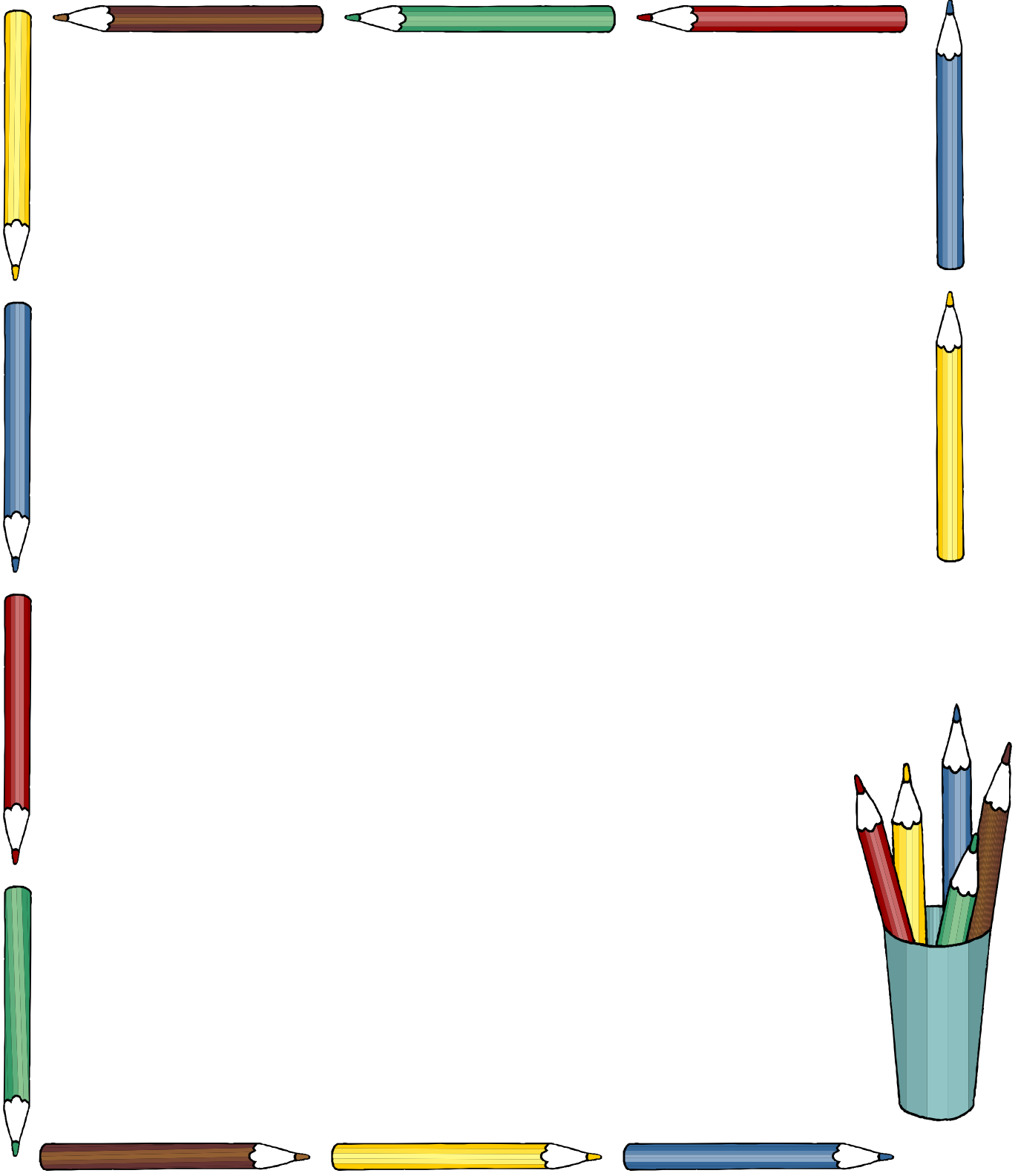
I would worry about whales though..."

"I would love to go and live under the sea; I could swim with the fish and make as much noise as I wanted. I could play games and go searching for treasure!"



"This is "blue-green crazy guy". He's crazy because he just likes to party so much. He loves being around people and having fun!"

Now it's your turn! Draw a picture of your happy place in the box below.



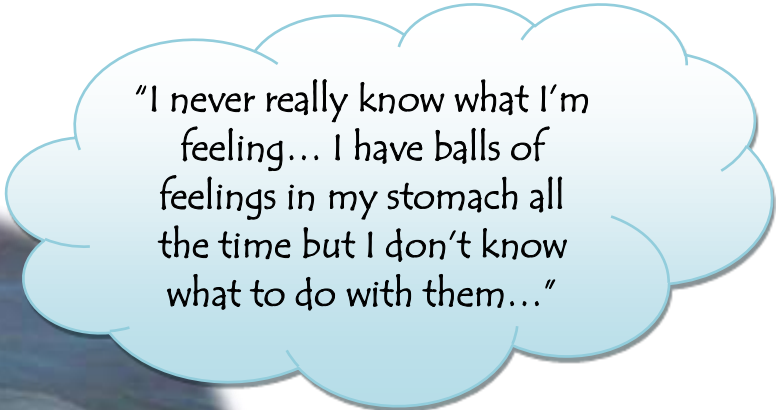
Thoughts & Feelings that You Might Think are Wrong

You might think that your thoughts and feelings are wrong. They might not seem okay and you might feel guilty for having them, but there is no right or wrong way to feel about what you are going through.

The most important thing is making sure that if these thoughts or feelings are scary to you, talk to someone you trust to help you work on feeling better. It is okay to ask for help.

Some thoughts or feelings that may seem wrong can be:

- Ⓢ "I wish this never happened"
- Ⓢ "I wish they just would have died"
- Ⓢ "They deserved what they got"
- Ⓢ "I wish they would just go back to the hospital and stay there"
- Ⓢ "I wish they would be back to normal, like they were before"
- Ⓢ "I don't want to help them... I think they're stupid and selfish"
- Ⓢ "I want to run away and never think about this again!"
- Ⓢ "I don't like this new person"



"I never really know what I'm feeling... I have balls of feelings in my stomach all the time but I don't know what to do with them..."



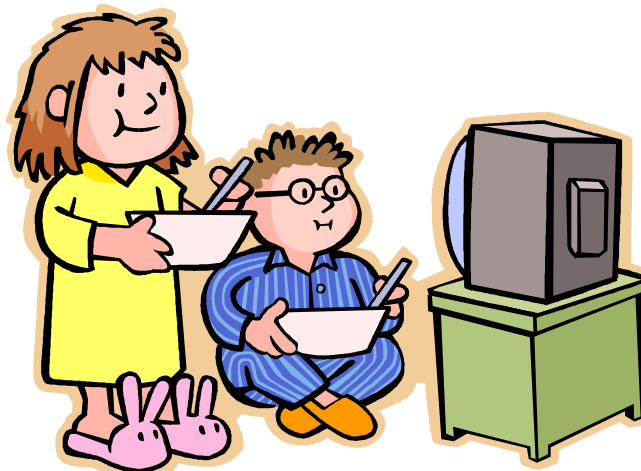
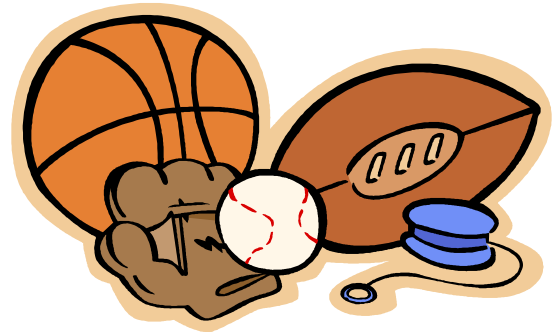
What Can I Do to Help?



"I hate it when my mom forgets all the time. It's her job to take care of us and she can't like she used to. She used to make our lunches in the morning before school and now I have to make mine and my sister's. I hate doing that. Now we have to have a lot more people around to help us with the cooking and cleaning and stuff since she can't do all those things anymore. I wish I had my mom back. I don't like this new person as much."

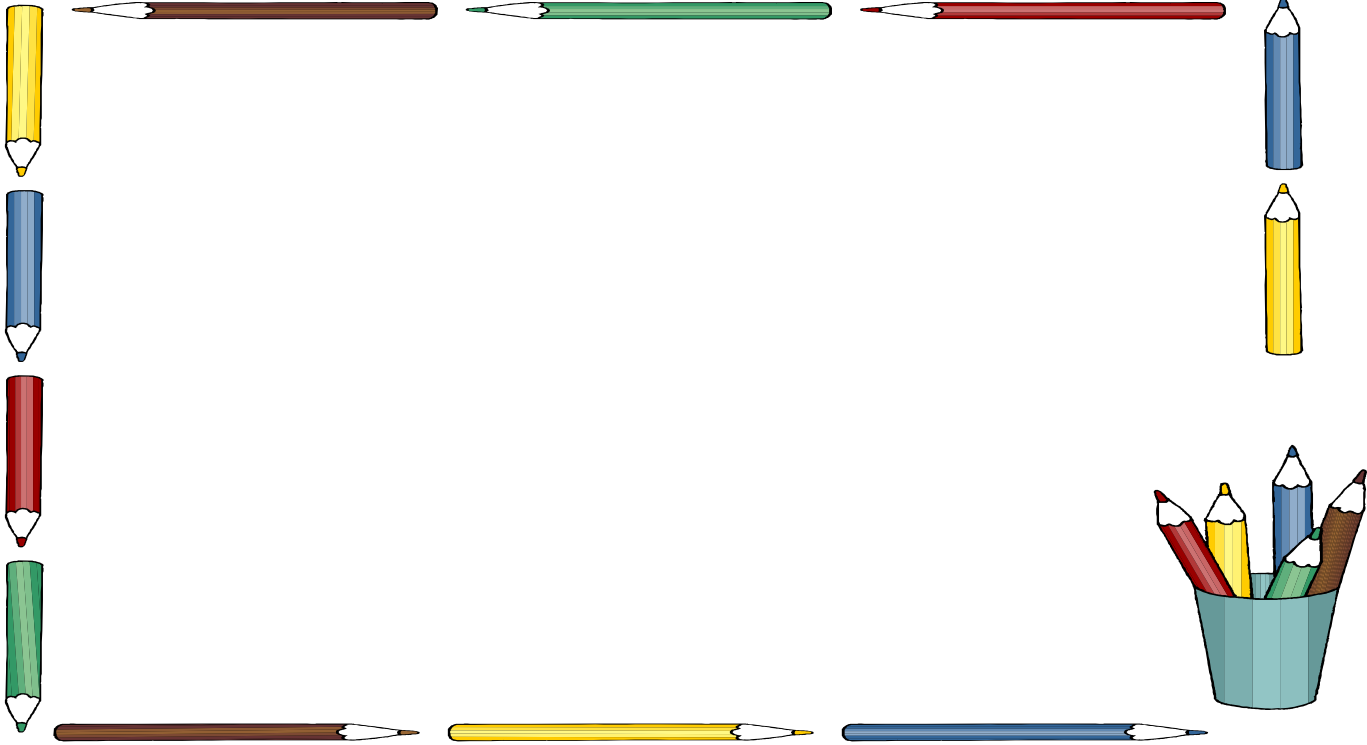
Sometimes the person that is hurt can't do the things they used to. This might mean that your parent(s) don't spend as much time with you as they used to. There are lots of small ways you can help them out and maybe you can all spend more time together.

- 🕒 Pick up your toys
- 🕒 Take care of your brother or sister
- 🕒 Put away your clothes
- 🕒 Play quietly when people are napping
- 🕒 Help keep the house clean
- 🕒 Give your pet some fresh water
- 🕒 Say "I love you" more often
- 🕒 Give someone in your family a hug
- 🕒 Help take care of your mom, dad, brother or sister



Draw a picture of what your family was like before the injury and another picture of what your family is like today. What kind of things have changed?

Before



After



What About the Rest of my Family?

Brain injury affects the whole family! Experiencing a brain injury in your family can make your home feel pretty stressful.

- Ⓜ Everyone in the family is having their own thoughts and feelings.
- Ⓜ Families can work together like a team to feel better.
- Ⓜ Everyone can use a hug and an “I love you” once in a while.



You might hear someone call the person who has the brain injury a survivor. Why?

- ② They survived whatever caused the injury.
- ② They survived the hospital stay, healing, and the changes that come after a brain injury.

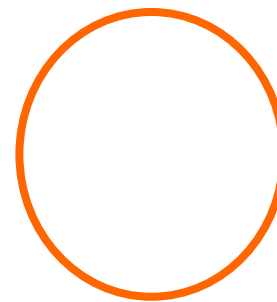
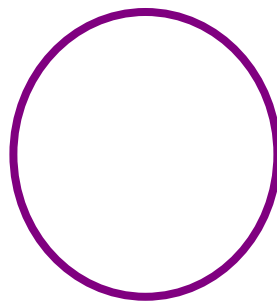
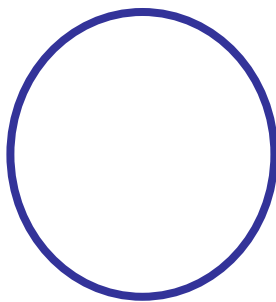
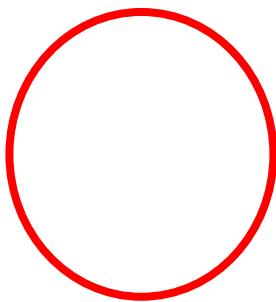
What is a Survivor?

Many survivors feel sad for what is happening to their families and themselves and try to hide the problems that they are having. Others don't realize that anything has changed.

They might be having the same kinds of feelings that you and the rest of your family are having.

What are Survivors Feeling?

Can you draw some faces in the circles below to show what kinds of feelings that a survivor of brain injury might be having?



"I feel like I am wearing a mask all the time... I feel like I have to hide what I am thinking and feeling because I don't want to upset anybody or make anybody worry about me."

In the Words of Survivors

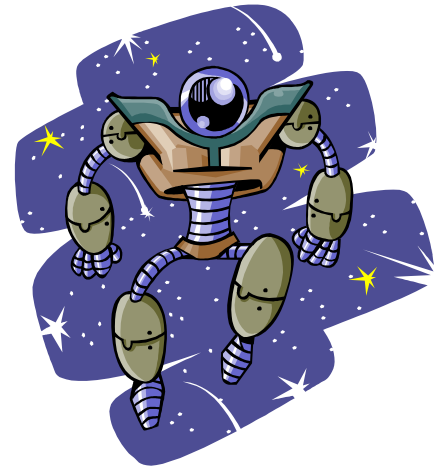
Survivors wanted to share their thoughts and feelings to help their families understand.

"Love me, not for who I was
But for who I am now."

"Sometimes I get so
frustrated I just want to
scream... but I know I
shouldn't, I should just
be grateful..."



"When I am tired – let me sleep
When I am confused – be patient
When I am sad – hold my hand."



"This picture is about aliens coming from Mars and Jupiter and the brown and orange boxes are traps set to catch the aliens. If he can catch the aliens, he will have some friends to play with."

Life after brain injury isn't always easy so it is important to celebrate every small step.

Celebrate!

"Sometimes we have to celebrate the smallest gains because they make us want to keep trying"



For Parents and Partners!

It's easy to reason that you were lucky because your child or partner survived the brain injury, but the uncertainties that follow are very difficult. It is very common for families to feel that since it is **their** loved one that is sick or injured, it is their responsibility to take care of them.

Some families don't ask for help because they think it may show that they can't care for their own loved one, or there is a stigma around brain injury so they don't want anyone to know what they are going through, or they don't know how to find help.

Without help, caring for a sick or injured person can be extremely stressful and life consuming. This can wear out even the most energetic person.

If you feel stressed and tired, it is harder to care for the person with the brain injury and any other family members who probably need you even more now.

In order to care for others, one needs to care for themselves first. Just like on an airplane when they say to put your oxygen mask on first and then help others. You need to do the same for yourself with self-care, counselling, time on your own and whatever else you need to "fill your cup" so you can get through the next day.

One of the most helpful things for a family that is new to brain injury, can be spending some time with others who have gone through it as well. Even though no two brain injuries are the same, situations and experiences can be very similar.

While there is no one that can really understand what you are going through, learning from other families can help prepare you and your family for the future.

"I was lost. I didn't know what to do or where to turn. One doctor was telling me one thing, another doctor telling me something else... I was so confused. When it was time to take my son home I thought I was ready. He seemed to be getting better so quickly. I remember thinking "he should be back to normal in no time!" I didn't need help from anybody; I could do this all by myself. He is my child and nobody can take better care of him than I could.

As time went on, I started to realize I was very wrong. Things had to get worse before they got better. My son's progress slowed and his frustration level increased. I was burning out at both ends. I started to lose hope... This isn't the way it was suppose to be! My son should have been getting more independent and becoming a man; instead he was almost completely dependent on me and seemed more child-like than ever before. I'm happy that it's never too late to ask for help, without it I don't know where we would be."


It can be very challenging dealing with all the emotions that come with a child or partner that is sick or injured. The feelings of guilt, shame and worry can be overwhelming. They can consume a person if not kept in check. Some family members report thinking:

- Ⓢ “Is this my fault?”
- Ⓢ “How is this going to affect our future?”
- Ⓢ “I am a bad parent/partner”
- Ⓢ “How could I let this happen?”
- Ⓢ “What did I do to deserve this?”

For the health and well-being of everyone in the family it is very important for parents and partners to take care of themselves physically, emotionally and mentally. Getting help from others is usually the best way to help everyone else.

Here are some ideas:

- Ⓢ Accept help from extended family members and ask for it when needed
- Ⓢ Do a help exchange with friends or family. Do something for them that works with your schedule (i.e.: make extra food for them when you are making a meal) in exchange for the help that you need.
- Ⓢ Talk to professionals
- Ⓢ Find experienced people to share with (such as local support groups)



Stay calm, be patient and ask for help before things get too overwhelming.

“My son was injured when he was pretty young. We thought we were lucky because he looked normal and could act okay at times. As the years went on, things got worse and the future was looking bleak. My husband and I divorced because we couldn’t agree on how to deal with all the trouble our son was getting into. Our family fell apart because we didn’t know how to ask for help. Over the years my son sustained several more brain injuries and he got in more and more trouble. He was even in trouble with the law a few times.

It wasn’t until I went looking for help that I realized that he was suffering from a brain injury and that there was help for him out there. With the right rehabilitation and supports, my son has learned to cope with his disability and learned to be independent and productive. I learned how to help him instead of enabling his behaviors while learning to help myself and what was left of my family. It’s never too late to get help and to turn your lives around.”

Grief and Loss

Families experience grief while their loved one is in a coma, experience grief when the brain injured person is changed by the injury, and everyone in the family including the person with the brain injury feels grief over what they have lost.



Grief is complicated when you face the pain of a loved one that passes away, but the loss after someone has a brain injury can be even more complicated. The person is still with you physically, but brain injury can change their personality and the dynamics of your family.

Dreams and plans for the future change in an instant and yet the person is right in front of you.

It is normal to go through the same stages of grief that you would go through if they had died.

Learning more about brain injury, how it affects everyone, understanding grief and loss and finding the resources you need to support yourself can be a first step in healing.

Resources for Parents and Partners:

<https://www.braininjurycanada.ca/en/caregiver/mental-health-caregiver/grief>

<https://www.braininjurycanada.ca/en/caregiver/mental-health-caregiver#SelfCompassion>

<https://cmha.ca/brochure/care-for-the-caregiver/>

https://www.healthcarecan.ca/wp-content/themes/camyno/assets/document/PolicyDocs/2012/External/EN/RespiteCare_EN.pdf

<https://www.braininjury-explanation.com/life-with-brain-injury/consequences-for-the-family/siblings>

<https://www.braininjury-explanation.com/life-with-brain-injury/loss-and-grief-after-brain-injury>

Children affected by brain injury in the family experience grief as well. While it can seem difficult to talk to a child about sickness or injury, it is important to be honest with them and help them to understand what has happened.

Children and Grief

- ⓐ Tell the truth in a simple, direct way.
- ⓐ Use concrete words that children know (sad, mad, sick, hurt ...).
- ⓐ If the child is quite young, it may help to use pictures, storybooks, toys and play to explain what has happened and how they feel.
- ⓐ Children are curious. Be prepared for questions and give them details simply and honestly.
- ⓐ If you are too distressed to answer your child's questions, ask an adult that you and the child trust to talk to the child.
- ⓐ Don't pretend that you are not sad - express your feelings to your child. This can help your child feel able to express their own feelings.

Like adults, children can be deeply affected by grief experiences. While everyone has different ways of grieving, common grief reactions in children include:

Reactions to Grief

- ⓐ Acting out feelings, rather than talking.
- ⓐ Changes in eating, sleeping and behaviour patterns.
- ⓐ Wanting to sleep in bed with an adult.
- ⓐ Displaying younger behaviors, such as wetting the bed or sucking their thumb.
- ⓐ Being angry, frustrated and restless.
- ⓐ Lacking concentration and energy at school.

Sharing Grief

Children, even at a very young age, can sense and experience grief. They will be aware if their parents or other adults are sad or having difficulties with a particular situation. Sharing your own feelings of sadness with a child can help them understand why you are sad and see that it is alright to express their sadness.

Sickness and injury can also cause children to worry about their parents or themselves getting sick or injured. Reassure them that everyone is safe and make sure that they are cared for during times of grief.

It is important to remain open and willing to talk about the various experiences of the situation. As children grow and develop, they will have different reactions to grief. A child who doesn't react to, or talk about, the changes in the early stages may want to talk about it later, or may show their interest and feelings in play rather than discussion.

Find professionals that can help you support your child such as counselors, a trusted teacher, doctor or nurse.

Where do I go for Help?

This is a very important question and not always very easy to answer. Many families come across their local Brain Injury Associations by accident or by word of mouth. We hope this section gives some ideas of where to look for help in your community or at least will get you and your family networking, which is an important step in finding the support and help most people need.

Find your local Brain Injury Association

Search the internet for local brain injury organizations, call 2-1-1, or get in touch with the community services in your town. Brain Injury Associations can be very useful in helping people negotiate government systems and finding services and resources that are relevant to brain injury. They sometimes offer support groups, case management and other programs for people with brain injuries and their families.

Local Community Services

Community Services usually have contacts and networks with other non-profit organizations in the area, which means they can be a great starting place for networking. This can include where to access support groups, food banks, counselors and many other services that can be very helpful.

Internet

Searching the internet can be very useful in finding out information on the brain, brain injury, local resources and support sites. Use a variety of key words until you find the information relevant to you. If you are researching information or resources, be sure to check your sources and make sure the site you are using is credible.

Specific Government agencies

Every province has their own government agencies which means that every province has a different way to access these services. Some of the services that can be accessed through the provincial government are Mental Health Services, Social Assistance (which usually includes Disability Benefits), Addiction Services and Health Authorities that may have brain injury programs).

The Fraser Valley Brain Injury Association is a non-profit organization dedicated to helping survivors and their families improve their quality of life through advocacy, education and providing case management. If you have any questions or comments about this booklet or acquired brain injury, you can contact:

Fraser Valley Brain Injury Association
201- 2890 Garden St.
Abbotsford, BC, V2T 4W7
Phone: 604-557-1913 Fax: 604-850-2527
info@fvbia.org www.fvbia.org



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